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Testimony in Opposition to Proposed Budget Cuts to DPH-Funded
Children and Youth with Special Health Care Needs

Honorable Committee Members:

My name is Cheryl Burack and I am the Executive Director of Family Centered Services of CT, Inc. I would like to strongly oppose proposed budget cuts to the DPH-funded CT Medical Home Initiative for Children and Youth with Special Health Care Needs program.

Children and Youth with Special Health Care Needs (CYSHCN) are children and youth age birth-21 who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount beyond that required by children generally.

The 2009/2010 National Survey of Children with Special Health Care Needs (CYSHCN) estimated there are approximately 139,453 children in Connecticut, ages 0-17 that have a special

health care need. This represents approximately 16% of all children in Connecticut who are in the 0-17 age range.

DPH currently funds five (5) care coordination contractors that provide care coordination services to children and youth throughout the State. Care Coordinators link children and youth and their families/caregivers to services and resources beyond the primary care site and even beyond health care, ensuring collaboration with schools, mental health services, social services, and other community based programs to make sure that these patients get all the treatment, services and supports they need to achieve optimal health, attend school and stay out of the emergency room.

Care coordination services are provided to the most medically and behaviorally complex children and youth, complicated even further because there is no single entry point to multiple systems of care. Anyone with a child with special health care needs understands the challenges of meeting that child's needs and the needs of other family members, ensuring that all providers are talking to each other and on the same page, making and keeping multiple appointments to various specialists, seeing that test results are sent to the appropriate involved doctors, that PPTs are scheduled, that medications and equipment are ordered, transportation is made available and community resources accessed.

Parents are often overwhelmed with the care of the sick child and their siblings, as they struggle to deal with a complicated and fragmented system of services and supports. Care Coordinators work to reduce the sense of isolation, intimidation and feelings of being overwhelmed that

families feel when faced with the need to navigate systems, learn and meet eligibility criteria, complete paperwork and understand various protocols and procedures. They educate families about the multiple systems that may be involved including medical, behavioral health, developmental, educational, legal, financial and human services and about the rights they have within each system. Through the implementation of Care Plans, they help link them to any other needed services, often providing transportation and accompaniment. Care Coordinators attend school and other meetings with CYSHCN and their families/caregivers and provide ongoing support.

Having already reduced staff due to prior funding cuts, the system is sorely underfunded and understaffed. In the regional program serving south central Connecticut, we currently have three Care Coordinators who have caseloads of 30 children each and we have a waitlist of 40. Our goal is optimal health for all children and this goal would certainly be undermined by the further reduction of these services.

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